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A Community-Engaged Assessment of Barriers and Facilitators to Rapid Stroke Treatment

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Abstract

Treatment for acute ischemic stroke must be initiated within hours of stroke symptom onset, and the sooner it is administered, the better. In South Carolina, 76% of the population can access expert stroke care, and rural hospitals may provide specialized treatment using telemedicine, but many stroke sufferers seek care too late to achieve full benefit. Using a community-engaged

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approach in a southern rural community, we explored barriers and facilitators to early stroke care and implications for improvement. The Community-Engaged Assessment to facilitate Stroke Elimination (CEASE) study was guided by a community advisory group to ensure community centeredness and local relevance. In a qualitative descriptive study, eight focus groups were conducted including 52 individuals: recent stroke survivors, family members, emergency medical personnel, hospital emergency department staff, primary care providers, and community leaders. From analysis of focus group transcripts came six themes: lack of trust in healthcare system and providers; weak relationships fueled by poor communication; low health literacy; financial limitations related to health care; community-based education; and faith as a message of hope. A hierarchy model for improving early community-based stroke care was developed through consensus dialogue by community representatives and the research team. This model can be used to inform a community-partnered, stake-holder-informed intervention to improve stroke care in a rural southern community with the goal of improving stroke education, care, and outcome.

Keywords

stroke; rural communities; community-engaged research; health care access; qualitative research; focus groups

Optimal stroke prevention and acute treatment requires effective engagement not only of people at risk for stroke, but the general population as well. Early studies showed fairly poor understanding of stroke, stroke risk factors, and critical actions during a stroke (Pancioli et al., 1998; Schneider et al., 2004). Especially critical for acute treatments, people must be aware of the warning signs and symptoms of stroke and the importance of utilizing 911 and pre-hospital services. Only with emergent transport and triage to a stroke center can acute reperfusion therapies be considered.

The only FDA-approved pharmacological treatment for acute ischemic stroke, intravenous tissue plasminogen activator (tPA), must typically be initiated within 3–4.5 hours of stroke symptom onset (del Zoppo, Saver, Jauch, & Adams on behalf of the American Heart Association Stroke Council, 2009). Pre-hospital delays, measured as stroke symptom onset to emergency department door time (ODT), remain a primary impediment to care. Fewer than 23% of 15,117 stroke patients from a North Carolina study arrived at an Emergency Department (ED) within 2 hours of symptoms onset (Rose, Rosamond, Huston, Murphy, & Tegler, 2008).

Minority patients are at risk for sub-optimal acute stroke care and outcomes (Davis, Vinci, Okwuosa, Chase, & Huang, 2007; Ellis & Egede, 2009). Pre-hospital delays have been found related to individual patient factors (i.e., knowledge, beliefs, health status), interpersonal factors (i.e., friends, family), health systems factors (911, emergency medical services [EMS], ED), and community readiness and capacity factors (Moser et al., 2006). Patients with awareness of the early warning signs/symptoms of stroke are more likely to use EMS (Lacy, Suh, Bueno, & Kostis, 2001; Morris, Rosamond, Hinn, & Gorton, 1999; Morris, Rosamond, Madden, Schultz, & Hamilton, 2000), thereby achieving shorter pre-hospital delays. Access for those at a distance from care was the aim of a test of the Remote Evaluation of Acute Ischemic Stroke (REACH) software program (referred to as REACH

Telestroke) in 12 SC community hospitals, using telemedicine to connect them to a major medical center to broaden the community's access to neurologic expertise, facilitate appropriate tPA administration, shorten hospital stays, and improve overall stroke treatment rates and clinical outcomes (Lazardis, DeSantis, Jauch, & Adams, 2013).

Studies suggest only minimal improvements in ODT are produced following single-level approaches (e.g., public health campaigns), and less inclusive methods are often costly, short-term and lack cultural relevance (Fogle et al., 2010; Lecouturier et al., 2010). Collaborative, multilevel, culturally situated community solutions are needed, aimed at creating sustainable community-level impact in patient behavior (Trickett et al., 2011). Guided by a social ecological model (SEM) that emphasizes the interrelatedness of the environment, persons, processes and context (Bronfenbrenner, 2005), and a community-engaged research approach (Minkler & Wallerstein, 2003), MUSC investigators and community partners in Georgetown County, SC conducted this qualitative descriptive study using focus groups. The aims of the study were to (a) identify and analyze individual, interpersonal, health systems, and community level barriers, facilitators, and implications to improve acute stroke care and (b) to develop a multi-component, culturally situated community model to improve care for acute stroke patients that will be tested in future trials.

Methods

Community Partners

A collaborative study entitled Community-Engaged Assessment to facilitate Stroke Elimination (CEASE) was built on a community partnership developed over 15 years ago between academic nurse researchers and the community in Georgetown County, SC, to improve health outcomes and reduce health disparities in African Americans with diabetes (Jenkins et al., 2004, 2010; Sadler, Newlin, Spruill, & Jenkins, 2011). The partnership was broadened to include hypertension control and stroke education in the community. Using a community-engaged approach, community-based organizations and academic institutions participated in the process of designing, implementing, and evaluating actions to support the health of the community (Community Campus Partnerships for Health, 2013).

Georgetown County is served by a single EMS service and hospital system. This rural county has 60,158 citizens, 20% over age 65, 33.6% Black, and with a per capita income of $24,437 (US Census Bureau, 2014). After study launch, the REACH Telestroke program partnered with the Georgetown Memorial Hospital (GMH) to provide emergent access to stroke expertise by utilizing real-time two-way video and audio assessment of acute stroke patients in the GMH ED.

An eight-member community advisory group planned the CEASE project, aiming to describe the barriers and facilitators regarding stroke access and strategies recommended by the stakeholders. The newly formed Georgetown CEASE Community Advisory Group (GCAG) and researchers regularly met in small and large group meetings and telephone conferences to develop the research design, implement research activities, review the analysis, and facilitate translation of findings to the community. A qualitative descriptive approach guided the data collection and analysis (Sandelowski, 2000).

Ethics and Sample

Following institutional review board approval, focus groups were planned. Focus groups were conducted at the Georgetown County Library Conference Room and at GMH classrooms. The GCAG and researchers recruited participants for the focus groups using the following steps: (a) the advisory group recruited Georgetown County citizens who had experienced a stroke in the past 5 years, as well as family members of patients who had experienced a stroke in the past 5 years; (b) the REACH Telestroke Program recruited GMH ED professionals and Georgetown EMS providers as well as local primary care and community providers; and (c) community leaders were jointly recruited by both the CGDC and the REACH Telestroke Program. Both purposive (focused on racial, gender, and age diversity) and convenience sampling was used. Recruitment included face-to-face contact, phone calls, and e-mail techniques. Of those recruited, 10 persons were unable to participate in the groups.

Eight focus groups were conducted with a total of 52 participants, of whom 39 were community members and 13 were healthcare providers. Two groups were composed of patients who had strokes within the past 3–5 years, two of family members of persons with stroke, one of community leaders, one of ED professionals, one of EMS providers, and one of local primary care and community health care providers. Participant characteristics are shown in Table 1.

Data Collection and Analysis

After discussing the research process and obtaining verbal informed consent, experienced focus group leaders conducted interviews using a focus group guide (Table 2) and probed for detail and clarity. Two team members took field notes and made audio recordings during the focus group discussions, which averaged 70 minutes. At the end of each focus group, the leader summarized what was discussed to ensure that the team had captured a general understanding of the group's comments. Each participant received a gift card worth $50. The digitally recorded interviews were professionally transcribed verbatim and verified for accuracy by both a community and academic member of the team.

Transcripts were analyzed using NVivo 10.0 (QSR International Pty Ltd., 2015). Two of the authors independently coded the qualitative data to describe the major barriers and facilitators voiced by the stakeholders and to identify stakeholders’ recommended improvements in stroke care in the community. One of the analysts represented expertise in community engaged research methods and health disparities, and the second was a qualitative research expert with more than a decade of broad qualitative analysis experience using NVivo, in a series of federally funded primary care studies.

Both analysts read all interviews and noted ideas within and reflected on key comments/ potential themes. Thematic analysis entailed reading the entire set of transcripts first, to become familiar with content and identify preliminary categories of data and codes to apply to data segments (Vaismoradi, Turunen, & Bondas, 2013). An initial small set of inductive codes was created based on the nature of the sample and the focus group questions. This process was followed by comparing and categorizing resounding themes. Upon completion

of coding of all transcripts by both analysts, an iterative process of reviewing, renaming, and finding relationships and patterns within the coded text was completed. Through this review, reorganization occurred by merging similar concepts, going from a level of more granular detail to a more parsimonious list, and concluding with reduction to the final set of overarching themes that could provide a starting point for intervention development.

The findings of the analyses were presented among the academic research team for validation of key themes and discussion of findings. Findings were taken back to the community advisory group and all focus group participants in a larger community forum. The forum was intended to disseminate preliminary findings and conduct member checking (Lincoln & Guba, 1985) to verify that the analysis represented a credible account of what the participants communicated in their interviews and that the concepts had face validity.

Results

Group members focused on barriers and community potentials. Four barriers were lack of trust with healthcare system and providers, weak relationships fueled by poor communication, low health literacy, and financial limitations related to health care. Two community potentials were community-based education and faith as a message of hope. These themes were voiced by all of the groups and point to priorities for interventions. While both barriers and community potentials were voiced, fewer community potentials than barriers were found.

Barriers

Lack of trust in healthcare system and providers—A prevailing barrier described in all focus groups was lack of trust. Rousseau, Sitkin, Burt, and Camerer (1998) defined trust as “a psychological state comprising the intention to *accept vulnerability* based upon *positive expectations* of the intentions or behavior of another.” All of the groups provided insight into issues of trust that needed strengthening, which is seen as key in reducing health disparities.

While there were some positive perceptions of trust, the trust was not always strong and durable, and there were gaps in the development of strong trusting relationships that invoked respect or facilitated relationships among providers and community members. Although each of the stakeholders came from different life experiences and had different worldviews, it was clear that many of the patients and community members lacked confidence that they would consistently have their needs met.

Stroke victims and their family members voiced mistrust of physicians and hospitals. Their mistrust diminished enthusiasm for going to doctors for prevention or management of a chronic disease. For example, one family member stated: “Why go to the doctor if you don’t trust ‘em? Why go to a hospital if you don’t trust the people in there? First you gotta trust yourself.”

In participants’ views, at the various encounters with the health care system, providers might not be counted on for timely access and culturally sensitive care. The issue of trust was

evidently realized by an EMS provider who stated: “I can’t help wondering if there isn’t a trust issue, also. Uh, not necessarily in everybody's case, but some people I hear express concerns about going to, like, our hospital system.” Another EMS provider commented, “I’ve set there for an hour and tried to talk people in to going to the hospital before.”

Opinions regarding treatment at the local hospital versus the academic referral hospital were mixed. Some expressed concern that the care may not be as good locally, but many did not know that these hospitals collaborated in a telemedicine stroke program.

Several participants also expressed they were not certain that they could always trust themselves to make the right decisions. Additionally, healthcare providers did not always trust that their recommendations were followed, and EMS personnel did not consistently trust that their assessments were valued by hospital team members from other professions.

Many community residents also had low trust that EMS services were reliable, prompt, or available in remote rural sections of the county. Residents expressed skepticism as they found themselves waiting for the ambulance or waiting in a crowded ED to be treated for what they considered was an emergency. A community leader stated, “EMS-they can easily take 15–20 minutes to get to you,” pointing out that rural access to emergency care necessitated self-reliance. A family member perceived a disparity in treatment in the ED: “If you have insurance, they take you right on in. You don’t have no insurance, you sit and wait.” Some participants expressed the view that doctors and hospitals are there to make money rather than help “us.”

Primary care providers reported they did not trust that their patients were taking prescribed medications or following through on medical advice that had potential to avert a stroke. While the primary care providers discussed multifactorial reasons for non-adherence, including the cost of medications and fear of adverse reactions such as coughing or impotence, their mistrust of the patients was supported by examples such as patients’ use of folk remedies. For example, one provider reported that when asked, “Well, are you taking your medicines?,” his patient replied, “No, but, that's cause I’m taking, I’m drinking some vinegar.” This provider perceived patients’ lack of trust in his recommendations: “And, they’ve, uh, talked to some of their family members who are recommending something that, like that, and they’re more likely to take their advice than they would be mine.”

Weak relationships fueled by poor communication—There was an expressed need to improve relationships and communication between the healthcare providers, staff, and EMS teams. Clear and direct communication is critical to maintaining relationships, but the EMS teams that transported specific stroke patients did not generally receive feedback or follow up regarding the outcomes of the patients brought in on stroke protocols. Similarly, a family member commented regarding a lack of relationship or communication with EMS providers:

> One issue that I’ve, I’ve had with EMS is when you call them and they come out and they give (get) the patient in the ambulance, they have no communication with the family. It's kind of like you just left out there and, um, and I think it would help if they were to say, “Well, you know, we trying to stabilize,” just have some kind

> of, you know, when, and I'm knocking on the door, “What's happening?” You know, tell me something, and they’re in the front of the house for a good 15 minutes and this, this was an incident when I really felt like my mother may have been having a stroke and I just couldn’t understand why, you know, that kind of behavior, where they just took her, got her in there, and just no more communication with us.

Improving relationships between the EMS team and patients and their families was viewed as an area of opportunity for this community. It was believed that by opening lines of communication and moving toward a more interactive educational process, the community could improve its involvement in promoting early stroke treatment. The patient–doctor relationship was somewhat difficult at times, as described by one primary care provider:

> I don’t get frustrated, I, I get more sad, I think, um, because I care, I care, I think we all care about our patients and we want them to have a good quality of life, and we don’t want them to have stroke, we don't (want) them to have to heart attack, we don’t want them to, you know, their diabetes to get worse and them to go blind and, so, we put a lot our caring into them and, so, when things go wrong, it's, it's upsetting.

A family member saw opportunities to improve the patient–doctor relationship:

> When you get to the see the doctor, you just have a few minutes but a lot of times, if you don’t have a discussion, the doctors don’t seem to have that much conversation. It's kind of like, you know, you’re in and you’re out. But, I found that if you ask questions, and you engage the doctors, you’ll get more information out of the doctors than, and, I’ve, I’ve had that experience, just the more you talk, the more engaged your doctor is gonna be. But, if you don’t engage in conversation, you kind of in and out.

Low health literacy—Health literacy is defined as “the degree to which individuals have capacity to obtain, process, and understand basic health information and make appropriate health decisions” (US Department of Health and Human Services, 2000). Providing health education alone does not necessarily promote behavior change, as social determinants of health affect the outcomes of health promotion activities (Nutbeam, 2000).

Providers, EMS staff and hospital staff, patients and family members discussed health literacy as a significant problem in the community. In focus groups of patients, researchers noted that some patients lacked clarity of knowledge, understanding, and decision-making, which indicated low health literacy on a continuum of skill attainment suggested by Schulz and Nakamoto (2013). For example, it was not well understood that time to treat stroke from the onset of symptoms was crucial. For example, one patient discussed symptoms not acted on quickly: “My hand was tingling, my feet and stuff … I was just joking about having a stroke, I ain’t know it was, you know, I was just joking that … you know, your hand go to sleep.”

Sometimes, limited understanding resulted in lack of ownership of symptoms. The ownership of symptoms is complex; the experience of health care disparities may influence the decisions to act on symptoms (Shearer, Jenkins, Magwood, & Pope, 2016). As described

by one family member: “I guess with some people they are afraid to hear what the doctor have to say. They don’t want to hear it again, and want to be in denial about the stuff.” Many persons in the community did not take blood pressure medications consistently as prescribed. One stroke survivor shared the following:

> I went to the doctor, the doctor gave me medicine, and being working and working and working, like, I didn’t went to pick up my prescription and take it, but I think if you get the, if the doctor tell you that you on blood pressure medicine, the best for you is to take the medicine. Now, I was hardheaded, when I came in, they asked me, cause my blood pressure was so high, she said, “Well, you on medication?” “Yes, ma’am, I was on medication.” She said, uh, “Were you taking?” I said, “No, ma’am, I wasn't taking it.” And, that's wrong behavior.

Family members stated that some of the elders did not understand what health professionals told them, further decreasing their desire to seek health care. One family member stated, “I mean, if you don’t know, you’re really not ignoring it, you’re just not knowledgeable of what's going on.”

Overall, the lack of stroke knowledge in the community was seen as an issue for which solutions were not easy. The need for education for the patients, family members and community leaders was voiced by all subgroups. One EMS provider stated, “Well, I don’t think it's, I mean, patient education is good, but family too. A lot of family members don’t know. They don't know what they’re looking at. All they know is mama's sick… They don’t know anything else.” Many family members agreed with a statement by one: “We need to educate ourselves so we can let someone else to know, and go forward.” It was clear that communication of information on stroke was needed in this community.

Financial limitations related to health care—Finances played a major role in the lives of the participants from the community. They described tolerating all kinds of health problems. They could not risk being sick from work, due to potential loss of income. Going to healthcare providers was not the norm for some participants. Limited insurance coverage and out-of-pocket costs were perceived as a burden. A stroke survivor mentioned his concern about not having money to pay for health care: “And, so, money plays a lot of part in, on your care. Uh, because if you don’t have it, you just don’t go, and most of us don’t go until we can’t take it anymore.” Health care visits were viewed as expensive, and patients were not sure they could afford the costs of emergency care and EMS use. They worried about how their bills would be paid, and they discussed that many people did not have medical insurance and as a result did not seek medical attention.

Simple interventions were seen as expensive and unnecessary even to insured patients. A stroke patient described the following:

> I went to the doctor's office on Monday, he read the x-ray because it was on the computer, he took the sling on my hand… the nurse took it off, then, after that, he said, “Yeah, hmm, put these two fingers together, and between these two fingers, put your fingers together, tape it up,” and he told me to come back in two weeks and that was $700 bill. Did I go back? No. I have insurance, but I said it's a rip-off.

A family member shared the perception: “A lot of people just not gonna go. Time you call EMS and come through the ER and get admitted to the hospital, people don’t know how these bills are gonna be paid. So they just better to ride it out.” A community leader stated:

> At the doctor's office, it says, “Payment is expected at the time that services are rendered.” … Doctor's gonna charge you $50 for a regular visit, you don’t make but $35 a day, you gonna give him your money? I’m gonna be in denial, saying, “Nah, it's not a stroke.”

Money to pay for medications was a concern. As one of the stroke survivors commented: “I think that's hard, cause my stroke, I was out of my medicine… waiting on payday.” Primary care physicians, ED staff and physicians, and EMS staff also were very clear that many community members did not take their medications as prescribed due to financial barriers. As one physician noted, “With my patients, it's always a finance issue.”

Community Potentials

While the focus groups pointed to many barriers, some facilitators were noted that could be leveraged to improve community-wide understanding and timely response to stroke symptoms.

Community-based education—A community leader discussed the success of more prevalent health education campaigns: “And, I think in, in Georgetown, I, you know, we do real good with diabetes. We do fairly well with cancer, especially breast cancer, but when you think about what kind of literature you see, even in the doctor's office, you don’t see a, um, stuff about strokes.” Another community leader described a worksite health education intervention:

> And, we’ve got a good program put together. I’ve got a great paramedic that works in health services department and is a fantastic instructor. I don’t know why he didn’t go on to medical school, because he could have. But his presentation, the signs and symptoms, to take and learn them, and then, have to sit down and take a quiz on it, they can teach you about urination and your color chart, what to look for, to recognize dehydration and things like that. I, I thank International Paper Company for putting a program together. If people have been educated, not only to help them at work, but they can take it home, too. So, education is a big thing.

Enthusiasm was noted for “healthy living” educational initiatives (e.g., programs from the American Heart Association) that reached out to the middle and high schools and included topics on stroke, diabetes, hypertension and heart disease. An EMS provider suggested health education in public schools:

> I been wondering if it could not be started, you know, they do health education in school, why could the health education not be kind of geared a little bit more to a broad nature with signs and symptoms of stroke for these kids in high school, signs and symptoms of other things. That way they kind of have an idea. And if you start educating the younger generations, even ones that are past 'em. If it starts now, twenty years we’re gonna have people out there that will have a better understanding of everything across the nation.

The patient focus groups also identified the strength of a high level of learning in the community from a variety of sources, such as responsive nurses, medical staff and EMS providers, and wise older community members and neighbors. As one patient stated, “You know, they, they have been here a long time, so, they could tell me something. I don’t know about anybody else, but like I said, um, they tell me a lot of things, and I listen to [them] they’re wiser.” Another noted that good habits and self-care were noticed in the community:

> By taking care of ourselves, exercising more, eating the right things, and, if they see that we doing the right thing and then, they gonna listen to you. If you do the right things, keep yourself, you know, preventing having a stroke, or any other things, you know, um, pertaining to the health position, and they see that you trying to do it right and they gonna to say, “Hey, she's doing a good thing.” … “Yeah, let's go and start doing some meetings.” They can start from you. Ourselves. Have seminars.

Another patient referred to the role of the community in facilitating positive action to address strokes:

> So, if the community would be more aware of their neighbor and what's going on in their community, I think it’ll help a lot because it could save my life. I might not knowing I’m having a stroke, but you knew someone who had a stroke, and you could be talking to me and see me having a stroke and you would detect that. But, see, again, community. You not going to be around a family member or a doctor or a church all the time, so, that's why the community needs to be more involved.

Faith as a message of hope—Faith was seen as a critical value to tap into in this community, and participants said that education could be achieved with support of the local churches. The community members believed that by adopting a message of empowerment and opportunities for treatment, their families and future generations might be better able to overcome the barriers to receiving effective stroke treatment. A primary care provider stated:

> I think community events would probably be a better way (to educate), you know, things through churches, um, places where people generally associate with having a good time. Um, to take a little bit of the moment in that good time, to do a little bit of education, um, on a longitudinal basis. I think that would be more effective than a reading material.

Patients also said that preachers and church leaders were key to helping convey positive messages about health. One remarked, “Cause a lot of them have health ministries at their churches, now, that get the information into the church.” An understanding of the symptoms and treatments of stroke was emphasized as vital to any educational effort within the community.

Agenda for Improving Early Stroke Treatment

The community forum highlighted the issues that need to be specifically addressed in and by all of the respective stakeholder groups. Figure 1 depicts the conceptual model developed after the community forum, as a hierarchy of needs related to improving early stroke treatment in Georgetown County. Health care needs to be prioritized, affordable, and patient

centered. Patients and family need to better understand the nature of the symptoms, treatment and the recommendations for their own self-management. The community is the best place to reach citizens to overcome their fear and mistrust of the medical and healthcare systems, and locations where people work, play, and congregate were suggested. Faith and the strength of the church can bring hope and awareness to this community toward improved healthcare behaviors. To facilitate good relationships between patients, the community and the healthcare system, the hospital and primary care environments need to reduce wait times and financial barriers and address prevention as a priority. The EMS system interfaces with all of these groups and can be a resource to all to ensure that protocols and resources are implemented in a learning and quality improvement paradigm.

Discussion

Many barriers within the community must be addressed to overcome the problems of delayed stroke care. Simultaneously, the facilitators can be used to strengthen and improve health care information and health behaviors in the community. These ideas provide a springboard for community interventions at the hospital, primary care, EMS level, and provide focus for the healthcare system to improve communication and achieve patient-centered care. Communication between healthcare personnel is essential to ensure that all team members feel competent to improve early stroke treatment. Communication can be built through development of learning health systems that also incorporate the voice of the patient and community members.

In our findings, low health literacy led to difficulty with making sense of stroke symptoms. Family and community views on medical services shaped much of the thinking and decision-making related to early stroke care. When Schroeder, Rosamond, Morris, Evenson, and Hinn (2000) examined determinants of EMS use in three urban areas, EMS use was more likely in patients with a high sense of urgency about their symptoms and when someone other than the patient noticed there was a problem. Negative experiences with physicians and/or hospitals were associated with lower frequency of EMS use. While our focus was a rural population, we noted similarly that past negative experiences had an impact on later use of EMS and ED services. Likewise, Skolarus et al. (2013) used a community-engaged approach with urban African American church teams in Michigan and found a need for recognition that stroke is a medical emergency, perceptions of difficulty within the medical system, and need for greater stroke education in community. We also found that perceptions and knowledge were the greatest barriers to emergent treatment of stroke and engaged the community for solutions that they could partner with health professionals to achieve.

In a comprehensive review, Cruz-Flores et al. (2011) found several sources of disparities in stroke care, including variation in socio-economic status and awareness of stroke symptoms, and misperceptions about available resources. They also identified mistrust of the healthcare system, religious and cultural beliefs, cultural isolation, access to transportation, and healthcare provider issues as system limitations that affected the disparity and quality of care among minority racial/ethnic groups (Cruz-Flores et al., 2011). Our findings corroborated all

of these issues and highlighted the need to improve trust, relationships, knowledge, and access to resources in rural underserved communities.

Translation of Findings and Lessons Learned

After discussion of these findings with community members and leaders, they recommended (a) further dissemination of study results; (b) the development of simple, appropriate, and easily understood messaging on stoke/stroke prevention; and (c) support for training and education of community and medical champions to educate their community about stroke. Additionally, plans to map stroke incidence in the county through geographical information system mapping and review of dispatch data from Georgetown EMS are underway. Community-based interventions are being planned to enhance collaboration between the local health care providers, EMS, and hospital teams to better understand the voice of the community and adapt programs and services accordingly. Telemedicine consultations are recent innovations in stroke care in this community; an effort is underway to seek appropriate utilization of these resources since they have been under-utilized. With shorter “onset to door time,” the sequelae of stroke can be improved. While not all communities are open to being a part of the solution, this community of Georgetown County is actively helping craft appropriate solutions.

Limits to generalizability of these findings should be noted. Our study was conducted in a singular small Southeastern community with a single hospital system that serves a population that is geographically dispersed across a rural county. Some key investigators had a pre-existing relationship to the community to improve outcomes of diabetes that facilitated entrée into the community, which may have produced findings different from those of other community-engaged studies. Despite these limitations, the findings have validity as demonstrated by validation by the target audience and their reach beyond immediate circumstances. Further research is needed to test dissemination and implementation of best practices in this community and to examine the impact of such community action.

Our future efforts to improve stroke care in this community are strongly aligned with Green and Glasgow's (2006) criteria that ecologic alignment is needed to implement improvements, and understanding of context is needed to maximize enabling factors and decrease exposure to health risks. The key lesson learned is that one needs to build trusting relationships to understand the community in order to intervene effectively.

Conclusions

We engaged patients, family members, EMS, physicians, and nurses within one county to identify not only the challenges to acute stroke care for high-risk communities but recommendations for improvement. The study results provide new insights and have contributed to ongoing community action in Georgetown County to improve hospital nursing, medical, EMS, and primary care responsiveness to the needs of the community. Findings add support for context-sensitive comprehensive multi-level interventions in areas where the needs of a population require significant collaboration and trust-building. Convening groups to prepare and disseminate appropriately tailored health education that fits the local context is critical. Factoring the needs and preferences of communities into care

delivery builds trust, especially when respective stakeholders learn how their input was used. Given that Gallup polls indicate nursing as the most honest and ethical profession, inspiring great public trust (Riffkin, 2014), nurses can play a leading role in improving community trust.

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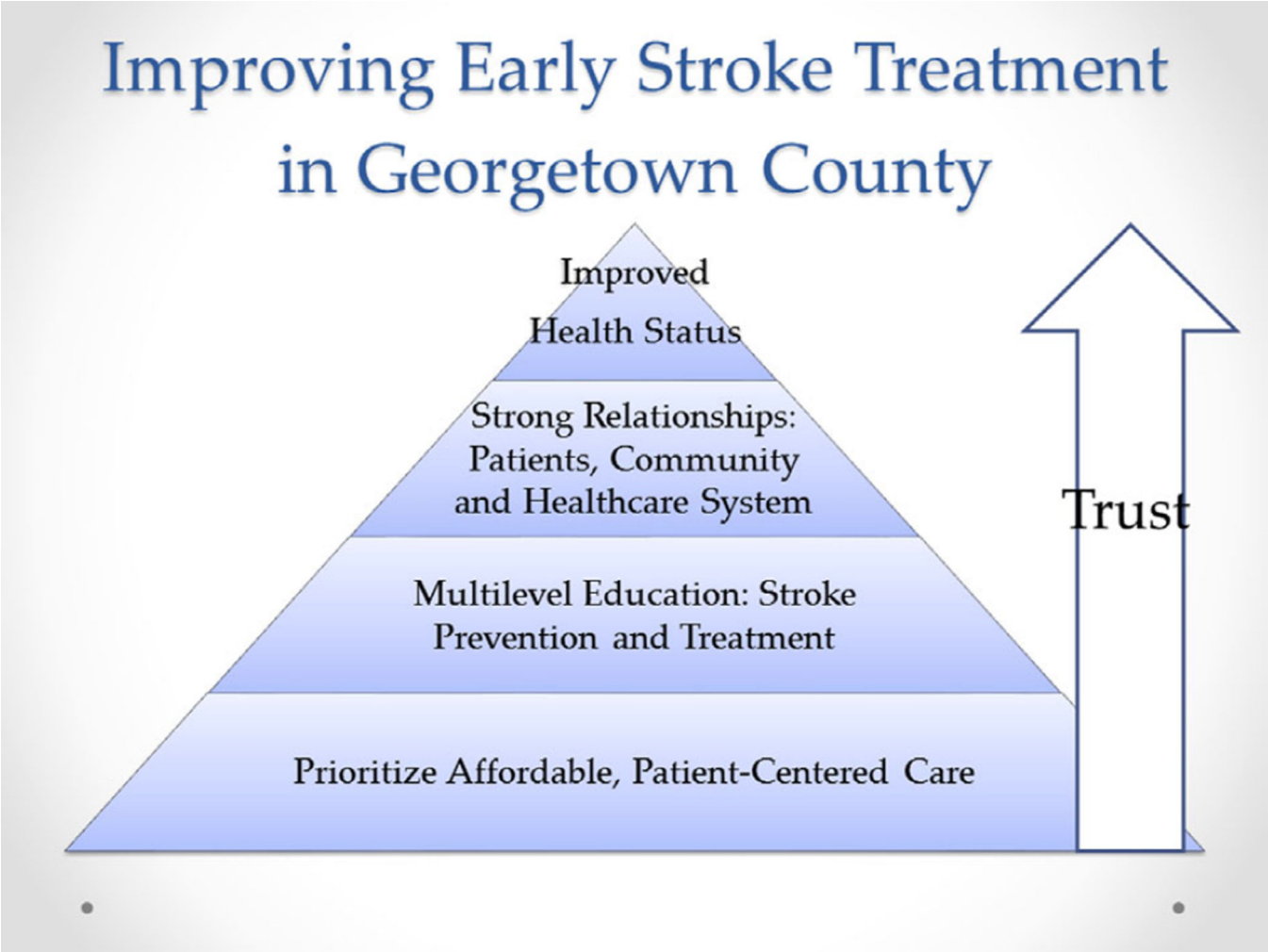

FIGURE 1.

Improving early access to stroke treatment in Georgetown County. The conceptual framework adapted with community input demonstrates a hierarchy of needs that must be met in order to improve health outcomes related to stroke in this southern coastal county. Trust will increase when each level of needs is met.

Table 1

Socio-Demographic Background of Focus Group Participants

	Community Members *n* (%)	Healthcare Providers *n* (%)	All Participants *n* (%)
Gender			
Male	11 (21)	7 (14)	18 (35)
Female	28 (54)	6 (12)	34 (66)
Total	39 (75)	13 (25)	52 (100)
Ethnicity			
Black/African American	37 (71)	3 (6)	40 (77)
White	2 (4)	10 (19)	12 (23)
Total	39 (75)	13 (25)	52 (100)
Highest degree earned			
High school diploma or GED	18 (35)	2 (4)	20 (39)
Associate degree	6 (12)	1 (2)	7 (14)
Bachelor's degree	5 (10)	3 (6)	8 (16)
Master's degree	2 (4)	1 (2)	2 (6)
Doctorate	–	5 (10)	5 (10)
Less than high school	3 (6)	–	3 (6)
Other	5 (10)	1 (2)	6 (12)
Total	39 (75)	13 (25)	52 (100)
Employment status			
Employed full-time	14 (26)	12 (23)	26 (49)
Employed part-time	3 (6)	1 (2)	4 (8)
Unemployed	6 (12)	–	6 (12)
Retired	4 (8)	–	4 (8)
Disabled	11 (21)	–	11 (21)
Other	1 (2)	–	1 (2)
Total	39 (75)	13 (25)	52 (100)

Note. Community members included 16 patients, 16 family members, and 7 community leaders. Healthcare providers included three emergency department personnel, four emergency medical system providers, five primary care providers, and one healthcare manager. Due to rounding, percentage totals may exceed 100%.

Table 2

Focus Group/Key Informant Questions

	Question	Follow-Up
1	From previous studies conducted in this community, some stroke patients in Georgetown are unaware of stroke symptoms. What are the major challenges in identifying symptoms of acute stroke?	Probe patients, families, EMS, ED, and also issues of knowledge trust, and beliefs/attitudes.
2	What are your thoughts about people who may be aware that they are having a stroke, but still delayed calling?	Probe issues of trust, denial, fear, access, cultural beliefs, and other barriers.
3	From previous studies, some REACH MUSC stroke patients arrived by ambulance and others did not. What are the barriers/challenges to activating emergency response systems?	Probe issues of knowledge barriers, trust, beliefs, dispatch priorities, field assessments, and communication systems.
4	What are barriers/facilitators to receiving local ED care?	Probe issues of knowledge barriers, trust, beliefs/attitudes, dispatch priorities, field assessments, and communication systems.
5	What are the barriers/challenges selecting health systems to seek care for strokes? Successes/facilitators?	Probe issues of knowledge barriers, trust, beliefs/attitudes.
6	Who are the key stakeholders to help improve these issues?	
7	What strategies are most feasible to increase recognition of stroke symptoms and reduce onset-to-door time for treatment of stroke?	Probe at each level: patient, family/friends, health systems, community.